"autism network"

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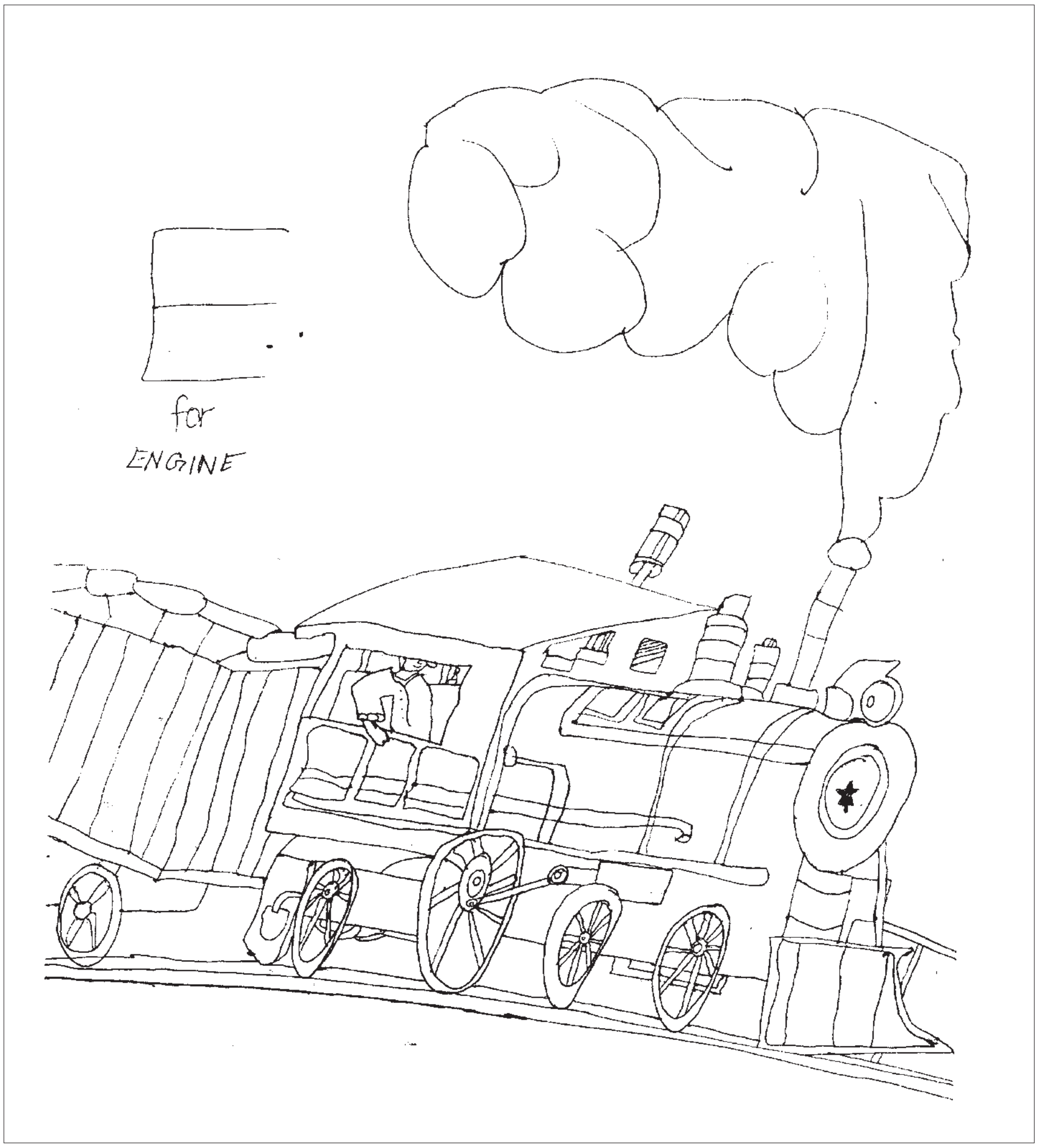

ACTION FOR AUTISM

autism network

APRIL 2010 **VOL 5 ISSUE 1**

Action For Autism is a registered, non-profit, national parent organisation. Autism Network is published by Action For Autism to provide information on education, therapy, care, and to provide interaction for families and professionals across the country.

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Sector 5, Jasola Vihar, Behind Sai Niketan, Opp. Gate 6
Sector 8, SFS Flats, New Delhi - 110025. Tel: 40540991/2

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The Editor, Autism Network at the above given address or
E-mail: actionforautism@gmail.com

Editor: Merry Barua
Editorial Board: Indu Chaswal, Nidhi Singhal, Indrani Basu
Design & Production: Bindu Badshah, Sudhir Pillai

In referring to the child with autism, Autism Network often uses 'he', 'him' and 'his', not as a prejudice against the girl child with autism, but for reasons of simplicity and because the vast majority of children with autism are male. However, many articles also use 'she', 'her', and 'hers'.

Website: *http://www.autism-india.org*
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As a centre that provides diagnostic assessments as well as life span counselling to families of children with autism, we often handle queries from concerned parents regarding alternative therapies. This issue we are pleased to carry an exhaustive article on Alternative Therapies by Mathew Belmonte. Mathew, an autism researcher based in New York, was in India earlier this year, and in him we found a reflection of our approach to the entire field of alternative therapies. Mathew has family members with autism, one being a brother who he has grown up with. He gave some wonderful talks at the National Centre for Autism and a few other places that were marked not just by knowledge and clarity of thought, but more importantly by deep empathy for families who live with autism.

I first came across some of these alternatives as a young mother early in the late 80s through Bernard Rimland's Autism Research Review International. Gluten and casein free diets, megavitamins, auditory integration therapy, these have all been with us for much more than a decade. Autism Network was the first journal in India to carry extensive articles on some of these therapies, particularly at a time when the internet was not as accessible as it is today.

With more families becoming net savvy, alternative therapies, some proclaiming miraculous recovery, are just a click away. And of course parents want to try out a therapy especially when that appears to be backed by anecdotal success stories. As Mathew says: 'How horrible would it be to discover, years later, that an unproven treatment might have worked if only a family had been willing to chance it without waiting for definitive proof.'

We know that some of these treatments can alleviate the symptoms of autism even if not the autism itself. We know that some of them are harmless, others not quite so. We know that educational treatments are a must; other treatments can be tried alongside but not instead of. Conveying this to emotionally vulnerable parents, in a manner that is supportive and sympathetic, is of the essence. Mathew's article says everything that a parent who wants to try alternative therapies, and is not sure how to go about it, needs to know.

Preparations for the 11th census of India are underway. The disability community has been active in trying to ensure that the process of enumeration of persons with disability is improved from the way it was in the last census, so that the numbers gathered are as close to actual numbers as possible. While efforts are on to ensure that the process of information gathering is made effective, it is also important for every person with disability and/or the family members to ensure that disability is noted when the enumerators come calling. When enumerators visit a household, they often fail to ask if there is any member in the family who has a disability. It is imperative that each one of us (overcome our sense of shame, stigma, embarrassment - if this be the case – and) volunteer the information, and insist and ensure that it is noted. If the numbers of persons with disability in the country show up as much less than they really are, then plan allocations on the disability sector will also be minimal. If real numbers are recorded, only then can sufficient funds be allocated.

A mention about Karan Johar's 'My name is Khan'. When one had first had heard about the movie: the protagonist having autism, being Muslim, and the entire plot set against the backdrop of 9/11, there was some trepidation as well as curiosity to see the outcome, and particularly to see how autism has been presented or 'misrepresented'. It was a relief to see that the subject has been relatively well handled and that the portrayal of autism is accurate even though of a somewhat 'all in one' fashion.

This has been an exciting year. Among other things, a second training on structured teaching took place at Bangalore and Delhi, and the 'Autism ACTION' team from Chicago helped with classroom setups in both cities, at Asha in Bangalore and AFA's Open Door School in Delhi. It is exhilarating as well as humbling to see how well structure helps individuals with autism deal with the world around them, and cope with their own difficulties. Challenging behaviours are 'magically' reduced.

We have been using structure in our classrooms for nearly 15 years. The workshop showed us how much more we still need to learn!

Alternative Therapies for Autism

Matthew K. Belmonte

Department of Human Development, Cornell University

What do we mean by 'alternative' therapy – an alternative to what? The term carries a connotation of novelty, of being outside mainstream science and medicine, and suggests that this mainstream may have failed to serve the people whom we care about. Although biomedical science has made faster and faster progress in understanding how autism spectrum conditions are caused, it is unfortunately true that these discoveries haven't yet translated into treatments that address these causes. Into this treatment vacuum, then, come the 'alternative' therapies, which have arisen outside the bounds of biology and medicine. In some cases they've been developed by parents or other caregivers, people with a deep, intuitive sense of how their children learn and what their children need. In other cases, they've been developed by physicians or scientists who work on the 'fringe' of biomedical science. Both the parents and the maverick scientists often lack proper scientific training. As a result their proposed therapies, though they may contain at least a grain of truth, are seldom subjected to controlled scientific evaluation. And without scientific study it becomes difficult to sort out what works and what doesn't work. This article aims, first, to give you tools with which to evaluate treatment claims: anyone can say that a treatment works, but how do you know when they've proven that it works? Second, we'll present some alternative treatment strategies that families can try, some of which can be implemented at home and some in consultation with a physician. Lastly, we'll critically evaluate some widely advertised but not-so-proven alternative therapies.

PART 1. What to look for in 'proof' of a treatment

The importance of scientific control

When people assert that a treatment is effective, they can be criticised by scientists for 'lack of control.' A 'control' is what we implement when we randomly split the set of people in the experiment into two groups, and apply our putative treatment to one of these two, keeping all other aspects the same for both groups. For example, if we're interested in whether a gluten-free diet might help with autism, we might assign some participants to a treatment group who are restricted to this diet and others to a control group who aren't. Or if we're interested in whether a certain way of teaching works for people with autism, we might assign some participants to a treatment group who receive the teaching and others to a control group who don't. Although it may seem unjust to deny treatment to half of the participants, this view actually begs the question: withholding a treatment is an injustice only when we are certain that the treatment works. If the treatment doesn't work, then we are doing a favour by withholding it! And only a well controlled experiment can tell us whether a claimed treatment actually does treat autism.

What makes a good control?

It's important, therefore, to get the control condition right: we want the experimental treatment to be the only difference between the treatment group and the control group. In the example of the gluten-free diet, it isn't enough just to bake gluten-free foods for the experimental group. We would need to bake exactly the same recipes for the control group, except with a measure of gluten added, and then we would need to restrict both groups to eating only those foods that we provide for them. This way, the taste, texture, calories, and amount of food for each group will be the same, and if we find a difference between the two groups we can safely attribute it to the presence or absence of gluten. Again, in the example of the teaching method, we could not just leave the control group out of school (or in school but out of direct contact with a teacher). Instead, we would have to make certain that they receive the same number of contact hours with the teacher, the same 'amount' of teaching, only not with the same teaching method as the treatment group. It's important that parents and other caregivers understand this concept of scientific control, and that they're able to see when claims are based on uncontrolled or poorly controlled observations.

Assignment to a control group

It's also crucial to consider how participants are assigned to the experimental group and to the control group. In order for the experiment to be sound, these assignments must be random. That is, a participant must be unable to choose which group (s)he will part of. Again this restriction may seem unjust, even heavy-handed, but let's think about what might happen if participants were able to choose: consider the parents who, because they believe that a gluten-free diet has benefited their child, sign on to be members of the treatment group but will refuse assignment to the control group. We would end up with a treatment group of people who are more likely to experience – or at least to report – positive effects, and so we wouldn't be able to know whether any difference between the groups might be an effect of the treatment, or simply an effect of the different memberships of the two groups! We would have a *confound* between treatment and group membership.

SIMILARLY, suppose that we've gathered experimental data on twenty people who've been on the gluten-free diet, and now we want to gather data on another twenty who are off the diet. This situation is a poor control, again, because participants aren't assigned to groups randomly: instead, everyone who joined the experiment earlier ends up in the treatment group, and everyone who joins the experiment later ends up in the control group. So there is a *confound* between treatment and time, and we're unable to know whether a positive result is an effect of the treatment or an effect of some other, unknown factor that changed between the time when the treatment group were recruited and the time the control group were recruited.

Outcome measures

When a treatment works, how do know that it works? It isn't enough to ask "Did this person get better?" We have to know what we mean by 'better.' Part of this involves knowing what the treatment is intended to accomplish, and how we might measure that accomplishment. It's important that these measures be *quantitative* and *objective.* We cannot, for example, rely on reports that a child seems more well-behaved – because such a general description can mean different things to different people; different families might have different ideas about what constitutes good or bad behaviour. So instead we must have a detailed and quantitative report – for instance, a log of specific behaviours that notes the time and duration of each, something like the detailed logs that are prepared during Applied Behaviour Analysis.

'Blinding'

In descriptions of scientific studies you'll often hear the term 'blind' or 'double blind.' A single blind means that the participants in the study are unaware of (or 'blind to') whether they're in the treatment group or the control group. In a double blind, the scientists are also blind to group assignment – that is, they ask someone else to assign people to the two groups, and only after taking all the outcome measures do they allow themselves to see the group assignments. Keeping the participants blind prevents placebo effects, in which positive results occur just because the participants believe in the therapy. And keeping the scientists blind prevents us from unconsciously biasing our outcome measures; this is especially important when the outcome measures can't be made 100% objective – for example, when there's room for some subjective interpretation in assigning a score. This blinding of the participants in the study and of the scientists doing the study is a lot like sequestering a jury during a trial: we want the result to be influenced only by the facts of the case, and not by any extra knowledge that the jurors might pick up.

Treatment group heterogeneity, or "If you've seen one person with autism, you've seen one person with autism."

Autism is defined entirely in behavioural terms: it's diagnosed when a person manifests restricted and repetitive patterns of behaviour and characteristic impairments in social and communicative functioning. But there is no definitive biological marker, no blood test, no problem that can be seen on a brain scan. Instead, every biological difference that distinguishes autistic from non-autistic people can be seen only at the level of populations, not at the level of individuals. So if we compare a hundred people with autism to a hundred people without autism, we do see differences in the brain. But if we pick just one of those people with autism and one without, we won't be able to look at their brain scans and predict which of them is autistic. And similarly, although hundreds of genes are likely to contribute to autism, each gene adds only a very small risk, and the odds are very small that any particular person with autism has a risk-associated variant of any particular gene. It's as though we're trying to sort out why a car's engine is running too quickly: the cause might be the ignition system, or the fuel valve, or the carburettor: one behavioural condition, many possible causes.

WHETHER or not a particular treatment works for a particular person can depend on what's causing that person's autism. So a treatment that helps one person might do nothing at all to help someone else, if the causes of the autism differ in the two cases. This variability in treatment response makes it more difficult to prove that a treatment works, in cases where it works for only a small fraction of the treatment group.

Do no harm

Families are understandably desperate for any treatment that might help the people they love. How horrible would it be to discover, years later, that an unproven treatment might have worked if only a family had been willing to chance it without waiting for definitive proof? Although this try-it-and-see attitude is understandable, it can expose families to a great financial burden at the hands of quacks and profiteers, and in some cases it can expose people with autism to great risk.

PART 2. Treatments that you can try

Historically, autism scientists have done a poor job of listening to autism families. As a result, many very commonly reported issues in autism – for example digestive problems, sleep problems, allergies and other immunological problems – were ignored by biomedical science for too many years. All of these issues have now been linked to biological causes of autism. And all of them can be addressed with biological treatments, even if the autism itself can't yet be.

Gastrointestinal problems

For years, parents have filled discussion groups and Internet email lists with reports of acid reflux, loose stools, chronic constipation or diarrhoea. These symptoms began to be taken seriously by biomedical science only when it was discovered – in 2006 by a multinational team led by Pat Levitt in the US and Antonio Persico in Italy – that a gene called MET is active both in the brain and in the digestive system, and is mutated in some cases of autism, and it's these cases that tend to come with gastrointestinal symptoms. And there may be other, still undiscovered genetic and environmental triggers that also affect both the brain and the digestion. Children with autism respond to stomach pain or to acid reflux in the throat much the same way that children without autism do: they may rub their bellies, cry, scream. When non-autistic children do this, we take them to a doctor. When an autistic child does it, too often we regard the behaviour as just another mysterious symptom of autism. If we paid attention to what these children are trying to tell us, we might be able to help them more effectively. This sensitivity to signs of distress is particularly important in cases where the person with autism lacks communicative speech. Is (s)he particularly upset after meals? Does (s)he grimace as though in pain? One strategy to try in such cases – one that is so safe that it can be purchased in all countries without a doctor's prescription – is a 'proton pump inhibitor' which inhibits secretion of stomach acid. (In India this is marketed as Dr Reddy's Omez Insta.) This is one case in which the treatment is so safe and so inexpensive that try-it-and-see actually is a good idea. In cases of chronically abnormal bowel movements, other strategies may be tried in consultation with a gastroenterologist. The point to emphasise is that although the causes of autism aren't yet treatable, gastrointestinal problems are very treatable, and people with autism deserve such treatment no less than people without autism. Physicians who are sceptical of the possibility of gastrointestinal disorder in autism should be asked to read Tim Buie's excellent article on this topic in the January 2010 supplement to the medical journal '*Pediatrics*'.

Sleep disorders

One child sleeps for only two or three hours each night. Another is up at 3 am but then drowsy in school. Another never seems to quiet down and fall asleep at night, and then has trouble waking in time for school in the morning. Sleep disorders are perhaps the single most disruptive element of autism for many families, not only disrupting the lives of autistic children but also preventing parents from getting their own rest, for years and years. In this case again, despite frequent reports from parents the symptoms were not taken seriously until a related gene was linked to autism. In 2007, a team led by Thomas Bourgeron at the Institut Pasteur in Paris discovered an autism-related mutation in ASMT, a gene responsible for making melatonin. Melatonin is a brain chemical which, amongst its other functions, regulates the body's sleep-wake cycle. Our brains manufacture more of it when we fall asleep, and less during the daytime. If we don't have enough melatonin, then many brain systems can be disrupted – some of them related to autism and some related to sleep. In this case again, although we can't yet treat the autism, we can easily treat the sleep problems by giving more melatonin. If your child has trouble with sleep, try giving melatonin at bedtime. You can start with a small dose and increase it. A typical dose for an adult is 3 to 5 milligrams. In this case again, the therapy is so safe and so inexpensive that it makes sense to try it and see.

Allergies or immune dysfunction

Autism has been linked to immune abnormalities. In some cases, relatives of people with autism may have auto-immune diseases, such as lupus or rheumatoid arthritis. People with autism may suffer from frequent infections (ear infections are often reported), and from allergic reactions (food allergies sometimes are noted by families). If you see unexplained skin rashes, or other symptoms that might indicate an allergic reaction, it may make sense to consult your GP or allergist, or simply to do your own tests at home, for instance by keeping a log of the foods that your child eats and the symptoms that (s) he has.

Drugs to treat symptoms

Remember that there is no current drug treatment that addresses the causes of autism. Until we know more about what these causes are and how they work, all that we can do with drugs is to treat symptoms. Remember this: drugs do not treat autism; psycho-educational therapies treat autism. A devoted and knowledgeable teacher will do more for your child than anything that comes out of a pill bottle. With that said, though, drugs can be useful insofar as they can control symptoms enough to give access to psycho-educational therapies.

For instance, a child may have such problems with aggression that it becomes difficult or impossible to keep him or her in the classroom. Or a child may be so hyperactive and distractible that it's impossible for him or her to focus on the lesson. Or a child may spend so much time on an anxiety-relieving repetitive behaviour that there is no time left for learning. In such cases, drugs can be a part – and only a part – of the solution.

These drug therapies should never be undertaken without the advice of a medical doctor. To control repetitive behaviours, the doctor may prescribe a *serotonin selective reuptake inhibitor* (SSRI). These drugs work by increasing the activity of a natural brain chemical, serotonin. Many SSRI's are available, and which of them is chosen often depends on the side-effect profile; many SSRI's have side effects including weight gain or insomnia, both of which may be issues for children with autism. For irritability and aggression, risperidone (Risperdal) or another *atypical antipsychotic* can be tried. (Although the name 'antipsychotic' refers to the use of these drugs to treat schizophrenia, they can also be effective in treating these specific symptoms – though not the causes – of autism.)

Symptoms of hyperactivity and distractibility in autism can mimic those in Attention Deficit Hyperactivity Disorder (ADHD), and just because a child with ADHD also has autism doesn't mean that (s)he can't be treated for the ADHD, using the same drugs that treat non-autistic children with ADHD. These drugs are methylphenidate (Ritalin or Concerta), amphetamine (Adderall), dextro-amphetamine (Dexedrin), or atomoxetine (Strattera, Tomoxetin, or Attentin).
No matter what you try, though, remember that the purpose of these drugs is to calm symptoms so that the child will have better access to psycho-educational interventions. Treating symptoms does little good unless you can offer the child a positive learning environment.

PART 3. Treatments with less evidence – and some with no evidence at all!

Vaccines do not cause autism

Some of the most unfounded ideas about autism have come out of the UK and the US. Without a doubt, the most harmful of these has been the **utterly false** claim that vaccines can cause autism. This claim is based on two **discredited** ideas. The first of these is based on a 1998 report by Andrew Wakefield and colleagues which claimed to find active measles virus in the colons of autistic children with gastrointestinal symptoms. This study, plagued by lack of control in recruitment of participants and in laboratory testing, was ultimately retracted by the journal in which it was published. This retraction, though, hasn't stopped vaccine opponents who claim that immunological challenge by the measles-mumps-rubella vaccine can push a sensitive immune system over the edge, leading to immune activation that results in autism. Whilst it is true that there is a strong link between immunological abnormalities and autism, it is not at all true that vaccines cause autism. We know this because several large studies have compared vaccinated and unvaccinated children and found no difference in the incidence of autism.

The second discredited idea about vaccines and autism is the notion that thiomersal, a preservative that contains mercury and is present in some vaccines, can cause autism in people who cannot rapidly eliminate toxic metals such as mercury. Although there have been reports that thiomersal can have toxic effects in brain cells and it seems a prudent precaution to have removed it from childhood vaccines, a 2003 study by Anders Hviid and colleagues in Denmark found that removing it from vaccines had no effect on the incidence of autism. This false claim of a link between vaccines and autism has caused vaccination rates to plummet in Ireland and Britain, and to some extent in the United States. As a direct result, thousands of children have contracted measles, and some have died from this entirely preventable infectious disease.
Vaccinate your children.

Chelation cannot help, and can harm or kill children

Proponents of the aforementioned mercury-poisoning idea in the US began pushing a procedure known as chelation, which is used to treat acute cases of heavy-metal poisoning. Their thinking is that if mercury causes autism, then removing mercury from the body might alleviate autism. Even if this claim were true, it seems to make little sense to try to remove mercury during later childhood or adolescence, many years after the damage has been done during infancy. Furthermore, chelation is not an entirely safe procedure; when misapplied it can do harm by removing beneficial metals from the body. In 2005, autistic five-year-old Abubakar Nadama died as a direct result of this chelation 'treatment.'

Do <u>not</u> try chelation.

Lupron 'therapy' cannot help, and can damage children's sexual development

Time and again we see poorly qualified people misinterpreting and misapplying true scientific results and theories about autism in order to support bogus treatments: the anti-vaccination movement uses proven immunological connections to support the false claim that vaccines cause autism, the chelation people use the fact that mercury is a neurotoxin to justify the false claim that autism symptoms are caused by mercury in the body. Perhaps the most absurd and dangerous of these misapplications, though, is a 'therapy' being marketed by American doctor Mark Geier. Geier begins with English psychologist Simon Baron-Cohen's evidence that high prenatal levels of the sex hormone testosterone may increase the risk for autism – this true finding about prenatal testosterone, though, is twisted by Geier into support for giving autistic children the drug leuprolide (Lupron). Leuprolide, a treatment for precocious puberty and for prostate cancer, amounts to a form of chemical castration. It may indeed decrease aggressive behaviour – in the same way that castration does.

Do <u>not</u> use Lupron.

Most 'sensory integration' therapies do not actually address sensory integration

Much has been made of Tomatis therapy and its relative Auditory Integration Therapy, methods of 'ear training' that claim to acclimate people with autism to certain sounds by playing them electronically processed voices and/or music. Neither of these methods has been proven effective in a controlled study. Nevertheless, practitioners often charge large fees for Tomatis or AIT 'treatments.' Although it is true that many people with autism have trouble integrating separate sensory channels – for example, trouble seeing and hearing things at the same time, or trouble paying attention to things in two separate locations at the same time – none of these sensory integration problems are actually addressed by Tomatis or AIT. Moved to action by the realisation that parents were spending large amounts of money on Tomatis therapy, in 2007 Blythe Corbett at the University of California Davis ran a double-blind study looking for any effect of Tomatis therapy on language skills in autistic children. She found that the control group actually improved their skills more than the treatment group! Although these claimed therapies cannot do serious harm, they cost money and they don't help.

The gluten-free and/or casein-free diet has been reported to help, but has not been proven

A diet free of gluten (wheat products) and/or casein (milk products) has for many years been reported to help in autism, but has hardly ever been examined scientifically. The idea began with the notion that fragments of proteins set free by partial digestion of gluten and casein might pass through a 'leaky' intestinal wall, and on entering the circulation they would mimic the effects of opioids – producing, for example, autistic insensitivity to pain. A related hypothesis is that partially digested proteins might provoke an immune reaction. Little or no direct evidence exists to support either of these hypotheses, but nevertheless there are positive reports from parents as to perceived effects of the gluten-free, casein-free diet. Probably because of the difficulty of controlling autistic children's food intake – an issue well known to parents! – only one double-blind study of this diet has been implemented. This study, reported in 2006 by Jennifer Elder and colleagues at the University of Florida, used blind quantitative ratings of children's behaviour and found no effect of the diet on behaviour. Nevertheless, some parents did maintain that they saw subjectively recognisable improvements when their children were on the diet.

If indeed the gluten-free diet has a positive effect, such an effect might simply be a general result of restricting food intake – especially in the subgroup of children with autism who have gastrointestinal problems: gluten-containing foods such as bread and pasta are a major source of carbohydrates, and therefore eliminating gluten can be expected to reduce total caloric intake and perhaps then to decrease associated gastrointestinal distress.

Facilitated Communication is a flawed method, but is at least not harmful if regarded circumspectly

In the 1970s Australian teacher Rosemary Crossley began supporting the hands, wrists or arms of children with severe cerebral palsy as they typed out, on a keyboard or a letter board, lengthy, intellectually deep communications despite being unable to speak or to communicate intelligibly in any other way.

This technique, 'Facilitated Communication' (FC) was never evaluated in a large-scale, controlled study but nevertheless was later extended to people with autism who lack speech, or who lack communicative use of speech. In 1989 the method was imported to the United States by Doug Biklen at Syracuse University. Later it came out – in the context of a series of false accusations that were produced by FC – that many practitioners of this technique were unconsciously guiding their clients' hands towards particular letters. Thus FC is a flawed technique that cannot, in general produce reliable communications. Almost every controlled study of FC has found that clients are unable to respond correctly to questions whose answers are not known to the FC practitioner. Nevertheless, there are several cases of people with autism who, after beginning FC with hand support from a practitioner, eventually progressed to typing independently without anyone touching them. Perhaps the most famous of these cases is Sue Rubin, who used FC, typing independently, to complete a university degree.

There are neurobiological reasons to believe that people with autism may be capable of more communication via a slow, untimed process such as typing than they are via rapid processing such as speech and spoken conversation. (My students Grace Chen and Keith Yoder have a paper in preparation addressing this topic.) And many parents who use FC with their children report that the children seem less frustrated when they're able to type. Even though the communications might not be genuine, then, in some cases FC may be worth trying just for its emotional benefit to a child who all of a sudden becomes respected and attended to, even if it's only as though (s)he were communicating – it's important to show faith in children's abilities and intellects. And in a few cases, FC may eventually lead to genuine communications without any practitioner involved.

Nevertheless, FC is a doubtful and error-prone technique, messages typed whilst being touched or supported by an FC practitioner should not be regarded as unequivocally true reports, and parents should be very wary if they are asked to pay significant moneys for FC therapy.

Rapid Prompting Method / Informative Pointing Method

Soma Mukhopadhyay, mother of autistic poet Tito Mukhopadhyay, developed a method of teaching that became popularised as the 'Rapid Prompting Method' (RPM). This intuitively based method was given its name by Portia Iversen, mother of Dov Shestack and co-founder of Cure Autism Now. Later, Ms Iversen further formalised elements of the technique under the name 'Informative Pointing Method.' The method begins by training clients to point to one or another of two alternative responses to a very easy question, such as "Is the sky red or blue?" or "What is one plus one?" Once the client has become comfortable choosing between two options, the complexity is gradually increased until the child is choosing amongst the twenty-six options available in the Roman alphabet. Importantly, the client receives no physical support or guidance from the practitioner (thus distinguishing this technique from FC); the only cues are non-specific ones aimed at re-orienting wandering attention – e.g. shaking the letter board in front of the client's eyes, speaking a command, or firmly poking the child.

RPM/IPM has not been subjected to controlled study, and until there has been a controlled study the authenticity of RPM/IPM-based communications must remain in doubt. For this reason, parents should be very wary if they are asked to pay significant moneys for RPM therapy. As is the case with FC, though, RPM/IPM seems to have brought certain clients to independent communication. The most notable of these cases is Tito Mukhopadhyay, who has written entire books.

My research group is continuing to investigate RPM/IPM, with the goal of conducting a controlled study to test whether the communications that it produces are authentic.

Conclusion: If it works for your child, and can do no harm, and doesn't cost, stick with it!

Unproven claims about alternative therapies seem to sprout like heads on a hydra; many more of them exist than can be enumerated in this article. I hope, though, that I've been able to give you a sense of what's out there, and what to look for when evaluating the many grand claims that you'll often hear.

Ask yourself the following questions:

- Does it work? Has the therapy been supported by a controlled study? If so, what was the study's level of blinding? Are the outcome measures objective, quantitative, and descriptive of the therapy's aim?

- How does it work? Is there at least a plausible mechanism by which the therapy could have an effect?

- For whom does it work? How many participants took part in the study, and did they all respond to the treatment in the same way? If not, were there any characteristics that differentiated the responders from the non-responders?

Do not believe everything that you hear. For every claimed treatment of autism, there is a story that "it worked for my child." As human beings, we often find it difficult to think in the abstract and aloof terms demanded by scientifically controlled experiments. We are driven, instead, by stories that are concrete and personal.

When we see that a treatment is applied and we see that a person improves, we're inclined to put two and two together, erroneously, imputing cause and effect. But what if this particular person would have improved anyway, even without the treatment? If enough people try the treatment, we're all but certain to find at least one who just happens to improve. That person often will have a parent who defends the treatment vociferously, almost religiously. It's difficult to blame these defenders of false therapies; they've found a treatment that they truly believe works, and they want others to have a chance to benefit from it. This is why I tell parents that if a therapy seems to work for their child, can do no harm, and doesn't cost much money, then keep doing it. There is value in it, even if all that it is a ritual of faith.

Further details on therapies that work and don't work can be found at http://www.asatonline.org/

Matthew Belmonte is a brother and uncle to two people with autism. Web site: http://www.mit.edu/~belmonte/

> *Take the first step in faith.*
> *You don't have to see the whole staircase,*
> *just take the first step.*
>
> \- Martin Luther King, Jr.

Disability and Census

Garima Pant

The National Centre for Promotion of Employment for Disabled People (NCPEDP) had organised a two-day National Consultation on Disability and Census in March 2010. During the last census the disability sector had succeeded in the inclusion of disability in the Census of 2001, after considerable effort. However due to the last minute nature of the efforts, the census did not yield accurate results.

THE Census 2011 will now be the fifteenth census of India. A sensitive and aware Census Commissioner of India, Dr C Chandramouli, has invited suggestions on the questions and inputs on disability for the instruction manual for enumerators to ensure that disabled people are accurately enumerated in the upcoming Census. To understand what kind of questions the disability sector thinks should be asked in the census questionnaire and to ensure that authentic disability data is collected, the NCPEDP circulated a questionnaire among leading disabled rights activists across various areas of disabilities and across the country. Their opinion was taken in the context of how the question on disability should be framed to ensure that disability is accurately reflected in the upcoming Census.

DURING the two day consultation, while a large number of participants favoured a functional approach to disability in the census, others also felt that given the levels of awareness in the country that unless disabilities were more specifically mentioned in a manner that was clear to both enumerator as well as respondent, the enumerators as well as the respondents would not come up with correct responses.

PROVIDING effective training to the enumerators is key to the colossal exercise of population census. The enumeration process will be starting shortly. The enumerator has to ask the questions relating to disability. However, many do not. Whether they do or not, every family must come forward to encourage the enumerator and facilitate the process of giving information related to disability in their family.

ACCURATE enumeration is essential for proper resource allocation and hence it's important to ensure that the message reaches across to as many families as possible.

A Look at the CBSE Guidelines to Schools on Inclusive Education

Garima Pant

The Chairman of the CBSE has on 24 December 2009 sent out a circular to all the Principals of the CBSE Schools, observing that many schools affiliated to the CBSE are not abiding by the earlier directive dated 29 October 2008, to ensure that no child with special needs is denied admission in mainstream schools.

THE circular emphasises that children with special needs can benefit from a classroom aide to help them keep pace with the class curriculum and describes an aide as an adult sitting along with the special child encouraging and motivating the child to move along with the class.

SCHOOLS are advised to allow parents to request for an aide, so that individual attention can be provided to the child that would enable the child to grow and learn along with other peers in the class.

IN addition, the circular encourages Individual Evaluation Programs for children with special needs and the setting of specific learning goals for each child. It also recommends schools to appoint special educators for this purpose.

ANY school which fails to provide attention to a child with special needs or makes a pretext of denying admission to any category of a differently abled child will be liable to stringent action even to the extent of disaffiliation.

Guidelines on Inclusive Education of Children with Disabilities advises all concerned school authorities:

1. To ensure that no child with special needs is denied admission in Mainstream Education.

2. To monitor the enrolment of disabled children in schools.

3. To provide assistive devices and the availability of trained teachers.

4. To modify the existing physical infrastructure and teaching methodologies for the needs of all children including those with Special Needs.

5. To ensure 3% reservation of persons with disabilities in all institutions receiving funds from the Government (under The Persons with Disabilities Act, 1995).

6. To ensure that all schools are disabled friendly by 2020 and all educational institutions including hostels, libraries, laboratories and buildings have barrier free access to the disabled.

7. To ensure availability of study material for the disabled like the ‘Talking Text Books’, reading machines and computers with speech software.

8. To ensure an adequate number of sign language interpreters, transcription services and a loop induction system for the hearing handicapped students.

9. To revisit classrooms to organize the education of Children with Special Needs.

10. To ensure regular training of teachers in inclusive education at the elementary and secondary levels.

☺☺☺☺☺

Here’s something amusing
that I thought I’d share…..
Chitra Venugopal from New Delhi

“His staff used the interlude to remove all
stationery items like pen stands, paper weights
etc. from his, as well as, other desks.
They even considered removing the glass top
from another table, but finally settled to putting
away just the electronic watch on it.”
Sounds like preparation for a visit from
one of our kids???

This is from *The Times of India, 8 March 2010.*
Guess what the article is talking about?
The Rajya Babha on Women’s reservation bill...
Our kids have one definite option of
professions...become MP’s!!!

आवृत्तीय व्यवहार

Repetitive Behaviours

इन्दू चसवाल

अधिकतर ऑटिस्टिक लोगों में रूढ़ीबद्ध या बार–बार लगातार किये जाने वाले आवृत्तीय व्यवहार पाये जाते हैं। ऑटिज़म से प्रभावित बच्चे एवं बड़े, ऐसे व्यवहार दर्शाते हैं और इनमें मग्न व लीन रहते हैं। अन्य विकासात्मक स्थितियों में भी ऐसे व्यवहार पाये जा सकते हैं।

आवृत्तीय व्यवहार क्या होते हैं ?

आवृत्तीय व्यवहार का अर्थ यहाँ इस प्रकार है, ऐसे व्यवहार जो व्यक्ति बिना किसी सोच–विचार के करता है। अनुसंधान द्वारा यह स्थापित किया गया है कि ऑटिज़म होने पर व्यक्ति अपने जीवन में परिवर्तन की अवहेलना करता है, समानता बनाये रखना चाहता है और एक ही तरह की क्रियाओं और व्यवहार रखना चाहता है। बहुत से ऐसे व्यवहार हो सकते हैं जो व्यक्ति ऐसी स्थिति में करेगा जब वह अधिक व्यथित या उत्तेजित होता है। इन व्यवहारों के रहते बच्चा अन्य सामान्य बच्चों की तरह ऐसे क्रियाकलाप में सम्मिलित नहीं हो सकता है जो उसके नित्य क्रम का हिस्सा नहीं होते।

आवृत्तीय व्यवहार क्यों होते हैं ?

यह व्यवहार क्यों होते हैं, इसकी पूर्ण जानकारी तो नहीं है, परन्तु बहुत से अध्ययन किये गये हैं और उनके परिणाम यह भी कहते हैं कि आवृत्तीय व्यवहार अति संवेदनशीलता के कारण होते हैं। यह भी माना गया है कि यह व्यवहार किसी विशेष अनुभव के कारण भी हो सकते हैं। जैसे– व्यक्ति शरीर को लगातार आगे–पीछे हिलाते रहता है जिससे वह किसी तनाव की स्थिति से राहत पाता है। या किसी मनचाहे विषय की चर्चा होने पर यह उसे टी.वी. पर देखने पर वह अपने हाथ हिलाने लगता है।

कुछ अनवेशक सुझाव देते हैं कि व्यवहार का संबंध ज्ञानेन्द्रियों द्वारा प्राप्त सूचनाओं के अनुचित प्रत्यक्षीकरण के साथ हैं। संवेदनाओं को यह व्यक्ति एक सामान्य व्यक्ति की तरह समझ नहीं पाते, जिससे मिलने वाले संवेदन एक अलग ही तरह से अनुभव किये जाते हैं। इसके फलस्वरूप व्यक्ति की प्रतिक्रिया भी अलग होती है। जैसे मनपसंद संगीत सुनने पर उंगलियों को आंखों के सामने हिलाना।

यह बात हमें ऐसा सोचने पर विवश करती हैं कि इन्हें हम ''सम्प्रेश्न'' के रूप में समझें या नहीं। एक ऑटिस्टिक बच्चे के लिए अपनी बातों का अर्थ ''यह मुझे अच्छा नहीं लग रहा है'' हो सकता है जबकि दूसरे ऑटिस्टिक बच्चे के लिए इसका अर्थ'' मैं इस स्थिति में खुश हूँ'' हो सकता है। चिकित्सक यह भी मानते हैं कि यह व्यवहार मस्तिष्क में होने वाले रसायन असंतुलन आम दिखने वाले आवृत्तीय व्यवहार के कारण हो सकते हैं।

ऐसे व्यवहार किसी भी प्रकार के हो सकते हैं। यह सरल शारीरिक क्रिया जैसे हाथ हिलाना, से लेकर जटिल शारीरिक क्रियाकलाप हो सकते हैं। आम पाये जाने वाले व्यवहार–

1. हाथ या बाहों को हिलाना
2. शरीर को गोल घुमाना
3. मांसपेशियों को हिलाना
4. आगे–पीछे हिलना
5. उंगलियों को हिलाना
6. सर पटकना

कई बार यह आत्म–उपमानित (सेल्फ इंजुरी) भी कर सकते हैं। सर पटकना, हाथों को अपने दांतों से काटते रहना, अपने चेहरे पर स्वयं मारना, दांतों को पीसना, कुरेदना आदि।

आवृत्तीय व्यवहार को कम कैसे करें ?

व्यवहारिक चिकित्सा के टेक्नीक, दवा, सेन्सरी इन्टीग्रेशन चिकित्सा द्वारा हम ऐसे व्यवहार पर नियंत्रण पा सकते हैं। परन्तु यदि हम बच्चे को ज़ोर–ज़बरदस्ती से रोकेंगे तो उलटा प्रभाव पड़ेगा ।

– अप्लाइड बिहेवियर अनालसिस (ए.बी.ए.) एक ऐसा इस्क्षेप है जिसमें हम सकारात्मक व्यवहार होने पर उस पर ध्यान नहीं देते। ऐसा करते रहने पर बच्चा अधिक सकारात्मक व्यवहार दिखाने लगता है, क्योंकि उसके फलस्वरूप वह पुनबिलक (रिएनफोर्सर) की आकांक्षा रखता है।

– रीपेटेटिव व्यवहार होने पर हमें कोई प्रतिक्रिया नहीं देनी होगी। परन्तु दूसरे समय जब व्यवहार उपस्थित नहीं रहता, हमें बच्चे को सिखाना होगा कि वह ''हाथ हिलाना'', ''डोलना'', इत्यादि कब और कहाँ कर सकता है। इससे वह निर्धारित यह सीखेगा कि ऐसे व्यवहार अकेले में, एक निर्धारित स्थान पर करने हैं। उसकी जो भी आवश्यकता है (ऐसे व्यवहार से संबंधित) वह यदि पूरी होगी तो वह अन्य स्थितियों में सही पहलु पर ध्यान दे पायेगा। (कक्षा में, घर में कौशल सीखते समय, घर के बाहर सामाजिक स्थिति में)
– साथ ही हमें बच्चे के लिए चित्र समय सारणी तैयार करनी होगी जिसे देखकर वह दार्शिक स्पष्टता द्वारा समझ जायेगा कि यह व्यवहार कब और कहाँ करने हैं।

– सेन्सरी इन्टिग्रेशन चिकित्सा (एस.आई.टी.) के लिए एक सही व्यवसायिक चिकित्सक द्वारा हस्तक्षेप आवश्यक है। यदि यह आवृत्तीय व्यवहार किसी प्रकार की संवेदिक दुष्क्रिया के कारण हैं तो बच्चे के अनुसार व्यावसायिक चिकित्सक (ओ.टी.) एक विशेष योजना बनाकर कार्य करेगा। बच्चा सकारात्मक व्यवहार सीखेगा जो उसके नित्य जीवन में काम आयेंगे और सेन्सरी परेशानियों के कारण होने वाले नकारात्मक व्यवहार कम हो जायेंगे। एस.आई.टी. द्वारा बच्चे का अवधान सुधरता है और वह सही एवं आवश्यक सूचनाओं को ग्रहण एवं संगठित करने लगता है।

– कुछ दवा केवल कभी ऐसे व्यवहारों को कम कर सकती है। परन्तु इनका सेवन केवल डाक्टरी सलाह के पश्चात ही होना चाहिए। कौन सी दवा, कितनी मात्रा में और कितनी अवधि की हो, यह जब डाक्टर की सलाह से ही होगा परन्तु यह समझ लेना अत्यन्त आवश्यक है कि ''दवा'' का प्रभाव निश्चित नहीं होता और यदि सही सलाह द्वारा न ली हो, तो इसका दुष्प्रभाव भी पड़ सकता है।

इस प्रकार हम देखते हैं कि ''आवृत्तीय व्यवहार'' एक ऐसी परिभाषा है जो कुछ विशेष व्यवहारों का वर्णन करती है जो ऑटिस्टिक लोगों में होती है। इन्हें ''सेल्फ स्टिम्यूलेटिंग'' या स्व–प्रेरणीय व्यवहार भी कहा जाता है। ऑटिज़्म से प्रभावित प्रत्येक व्यक्ति विशेष है, उसके व्यवहार भी अलग होंगे और ऐसा भी होता है कि यह व्यवहार किसी व्यक्ति में अनुपस्थित होंगे। आकस्मिक कौशल रहने पर भी वह सम्प्रेषण एवं सामाजिक कौशल में कठिनाइयों के कारण सही ढंग से पढ़ाई नहीं कर पाते। उन्हें सामान्यकरण कठिनाईयाँ भी होते हैं। यदि स्कूल में शिक्षक ऑटिज़्म के प्रभाव को नहीं समझते तो बच्चे के व्यवहार को ''समस्या'' के रूप में देखने लगते हैं, जिसका समाधान उन्हें नहीं मिल सकता।

परन्तु कुछ स्कूल ऐसे भी हैं जहाँ समावेशिक शिक्षा अच्छी तरह चल रही है। सरकार भी प्राथमिक शिक्षा में ऑटिस्टिक बच्चों के समावेश को प्रोत्साहित कर रही है।

ऑटिज़्म–निदान के पश्चात्

Autism - What After Diagnosis

इन्दू चसवाल

आटिजम एक जटिल विकार है। इसके लक्षण जीवन के प्रथम तीन वर्षों में उभरते हैं। कई बार तो बच्चे के पहले 18 महीनो में एक सामान्य विकास दिखाई देता है। बड़े शहरों में निदान 2–4 साल में मिल जाता है परन्तु बहुत से ऐसे शहर, कस्बे और गांव हैं जहां पर अभी ऑटिज़्म का निदान मिलना कुछ कठिन है। "आपकी अन्तरा" और "माई नेम इस़ खान" जैसे धारावाहिक और फिल्मों ने जागृकता फैलाई है परन्तु अभी भी किसी भी प्रकार की विक्लांगता को "अन्तरा जैसा बच्चा" समझ लिया जाता है।

जब माता–पिता को पता चलता है कि उनके बच्चे को "ऑटिज़्म" है, तो स्वाभाविक है कि उन्हें धक्का लगता है। उनका संसार उलट जाता है। सबसे पहले "घबराए' ना"। परिवार को याद रखना होगा कि ऑटिज़्म एक ऐसी स्थिति है जिसमें अनेक चुनौतियां होती हैं, परन्तु यह कोई भयानक स्थिति नहीं है। इस लिए घबराहट ना करें। यदि परिवार शांति और स्पष्टता के साथ विचार करेगा, तो बच्चे और परिवार के सभी सदस्यों को लाभ मिलेगा।

<u>ऑटिज़्म के विषय में सही जानकारी प्राप्त करें</u>

सर्वप्रथम ऑटिज़्म को समझना होगा। कई बार शिशु चिकित्सक या मनोवैज्ञानिक भी इस स्थिति की उचित जानकारी नहीं रखते। या फिर माता–पिता को इसके बारे में जानकारी देने के महत्व को नहीं समझते।

निदान मिलने पर माता–पिता के पास एक नाम तो आ जाता है परन्तु इसका अर्थ, इसका उनके जीवन पर और बच्चे के जीवन पर क्या प्रभाव होगा, वह समझ नहीं पाते। एक पिता का कहना है, कि अपने बच्चे के निदान के पश्चात् वह अपने डाक्टर से पूछने गये कि "अगला कदम" क्या होगा परन्तु उन्हें निराश लौटना पड़ा। तब उन्होंने तय किया कि वह स्वयं जानकारी लेंगे। वेबसाईट द्वारा उन्होंने ऑटिज़्म की जानकारी प्राप्त की और समझने की कोशिश की। उन्हें धीरे–धीरे अपने बच्चे के व्यवहारों की समझ आने लगी। ऑटिज़्म को उन्होंने केवल एक परिभाषा के रूप में नहीं पढ़ा। उन्होंने अपने बच्चे में ऑटिज़्म के प्रभाव को समझा। इस प्रकार उनमें अपने बच्चे के प्रति स्वीकृति आई और वह "अगला कदम" चुन सके।

ऑटिज़्म से संबंधित जानकारी का भण्डार इंटरनेट पर उपलब्ध है। परन्तु इंटरनेट की "सूचना मंडी" को छांटना होगा। केवल माननीय और ऐसी जानकारी को ग्रहण करना होगा जो विश्वसनीय वेबसाईट द्वारा दी जा रही है और जो सही और सिद्ध अनुसंधान पर आधारित हो। इस लेख के अंत में कुछ ऐसी जानकारी दी गई है।

प्रारंम्भिक हस्तक्षेप

बच्चे की ब्रेन (मस्तिष्क) जीवन के प्रथम तीन वर्षों में परिपक्व होती है। इसलिए पहले 3–4 वर्षों में मिलने वाला संवेदन अत्यन्त महत्वपूर्ण होता है। सामान्य जानकारी यह कहती है कि निदान मिलने के पश्चात् माता–पिता को नज़दीकी चिकित्सक के पास दौड़ लगाने की जरूरत नहीं है, उन्हें चलकर पहुंचने की जरूरत है। आरंभिक इन्टरवेनशन को सर्वोत्तम परिणाम की कूंजी माना गया है।

हम जानते हैं कि पूर्व स्कूली बच्चों पर शिक्षा का पढ़ाई–लिखाई का दबाव नहीं होता। उनकी आदतें भी अंकित/स्थापित नहीं होतीं। इसलिए उन्हें सकारात्मक

ढांचे में रचा जा सकता है। इसलिए शीघ्रता के साथ प्रारम्भिक हस्तक्षेप आरम्भ करना सही माना गया है। ऑटिज़्म से प्रभावित बच्चों के लिए यह कार्यक्रम निम्नलिखित कौशल उभारने पर केन्द्रित होता है :

1. अवधान–कौशल

ऑटिज़्म से प्रभावित बच्चों का ध्यान किसी क्रिया या वस्तु पर लाना या हटाना कठिन हो सकता है। इसलिए अटेंशन या अवधान पर काम किया जाता है। बच्चे को आंखों से सम्पर्क मिलाना, पुकारे जाने पर प्रतिक्रिया देना, बैठकर कार्य करना, सरल आदेश (ले–लो, दे–दो) का पालन करना सिखाया जाता है।

2. संवेदिक एकीकरण कार्यक्रम

बच्चे में सही प्रत्यक्षीकरण प्रक्रिया इस कार्यक्रम से दी जा सकती है। अपने वातावरण को ज्ञानेन्द्रियों द्वारा समझना तथा संवेदनशीलता पर काम किया जाता है। नित्य जीविका क्रियाएं जैसे खाना, टाईलेट, कपड़े पहन पाने पर भी काम किया जाता है।

3. विशेष–शिक्षा

बच्चे को सरल क्रियाओं द्वारा निम्नलिखित कौशल सिखाये जाते हैं :

1. वस्तुओं में दार्शिक भेदिकरण द्वारा मैचिंग, सॉरटिंग।
2. अपने आसपास पाई जाने वाली वस्तुओं के नाम।
3. आम दिखाई दिये जाने वाले जानवर, फल, सब्जियों के नाम।
4. रंगों की पहचान
5. अंकों की पहचान
6. अक्षरों की पहचान

प्रारम्भिक हस्तक्षेप से बच्चा कितना ग्रहण करेगा, यह उसके स्तर पर निर्भर करेगा। प्रत्येक ऑटिस्टिक बच्चा अलग होता है, उसके गुण और कठिनाइयां अलग होती हैं। इस कारण वह अपनी गति से सीखेगा। परन्तु यह निश्चित है कि यदि उसके लिए व्यक्तिगत कार्यक्रम उचित ढंग से विकसित किया जाये तो वह अपनी सर्वोत्तम कौशल की प्राप्ति तक पहुंच जायेगा। प्रारम्भिक कार्यक्रम के अन्तर्गत माता–पिता की ट्रेनिंग से वह अपने घर के वातावरण के साथ रहता है, उनकी ट्रेनिंग से वह अपने घर के वातावरण को बच्चे के सीखने व समझने के अनुकूल बना सकेंगे।

स्कूल–विशेष शिक्षा या मुख्यधारा में समावेश

प्रारम्भिक हस्तक्षेप का लक्ष्य होता है– स्कूल के लिए तैयार करना। बहुत से ऑटिस्टिक बच्चे उचित प्रारम्भिक हस्तक्षेप के पश्चात् मुख्यधारा स्कूल में जाते हैं, परन्तु उन्हें एक समर्थ कार्यक्रम की आवश्यकता पड़ सकती है क्योंकि इस कार्यक्रम से वह मुख्यधारा स्कूल में और अच्छी तरह काम कर सकेंगे ।

Generalisation of Skills

Teaching K the concept of matching
had been an uphill task. But,
through perseverance, K had just got
the concept. Sometime during this period,
K's ailing, aged paternal grandmother passed
away.

In accordance to Hindu mourning customs,
K's father (Baba)
and uncle (Jethu) shaved off their hair.
So, enter Baba and Jethu
after having shaved off their hair.
K walks up to them, brings their heads
together, and says "MATCHING"!
Now, we definitely knew
that the concept of matching
was here to stay!!

HELPLINE

Since the two questions below deal with the issue of the use of aversives to deal with difficult behaviours in people with autism, the answer to the questions have been clubbed together.

Q A parent whose child is an ex-student of a very reputed special school in Mumbai has brought to our notice that the school has a seclusion room. The room is about one metre by one metre in area and is painted black from within. It has no light and little ventilation. The door has half a dozen padlocks on it from the outside. When a child is particularly unruly, upset or having a tantrum, he/she is locked up in solitary confinement here until he/she has calmed down and begs to be let out. As students of psychology, we are concerned with this practice. The parent was told that this practice works particularly well for children with ASD, but only those that can express themselves in speech. Is this true?!

Q A particular school in Mumbai that specializes in ASD believes in slapping children right across the face and also hitting them on parts of the body. The person who has set up and runs this school routinely does so even in the presence of the child's parents.. The 'reasoning' offered is that "children with ASD have less behavior problems if dealt with firmly". Most parents hesitate to question the person's actions and reasoning as they fear that their child will not be welcome in the school anymore or worse still, that their child will be picked on and hit even more in the parents' absence. How does one deal with such a situation? Does it help at all to deal with ASD children in this manner?

A Thank you for bringing up the issue of the use of aversives for dealing with difficult behaviours in people with autism. It is an issue that is often brought up by parents as well as concerned professionals working with people with autism and one that seems to elicit questions with regards to the effectiveness of such procedures. Unfortunately both parents as well as professionals often justify the use of violence against children with autism.

Behaviours that are seen as challenging are a form of communication given the difficulties that children with autism have in understanding communication and expressing themselves. Sure, we need to be 'firm', consistent, and clear in our communication and in helping with behaviours. However, firm does not equate with violent. Instead we make our children follow through with instructions given to them and we follow through on what we say to them. We also keep in mind that behaviours always happen for a reason though the reason may not always be apparent to us. Behaviour is the result of a person's history and his current environment. Every behaviour serves a function: it gets the person something he wants (something to eat, drink, go out etc), gets him attention, gets him out of a situation or activity that he does not want or finds unpleasant, or gives him some sensory inputs, and so on. If we treat the behaviour symptomatically, the behaviour may go away in the current situation, but will resurface because we have not been able to address the root cause of the behaviour. Its something like this: Say one has a fever, and you give the person a paracetemol. If the fever were the result of a stomach infection, the paracetemol will take care of the fever for a little while; but it will resurface. To get complete relief from the fever we would need to check WHY the fever is happening…is it because of a throat infection, a stomach infection, a viral infection? It is only when we treat the underlying cause of the fever that we will be able to stop the fever recurring. This applies to behavior as well. So, any strategy to deal with a challenging behaviour will need to address the root cause of the behaviour.

Punishment and aversives are often believed to be synonymous. However, punishment is about bringing down a behaviour; it is **not about retribution or retaliation. It is not about** making the individual 'pay' for 'inappropriate' behaviour**.** If we are going to be using an aversive as a punishment technique, we have to see whether the behaviours for which this aversive is being used goes down. It is not sufficient for the behaviour to stop occurring in just the current situation, but it is important for the behaviour to reduce and stop occurring in the future too. It is only when this happens that we can say that the use of punishment has been successful.

The very fact that in the two situations the behaviours for which the children being locked up in the dark room, and being hit across the face, have not gone away shows the futility of such methods, apart from being a violation of human rights.

In the use of aversive, there is another thing that one needs to be careful of, and that is the aspect of observational learning. Every time we hit a child when he has done something we don't want him to do, we are teaching the child that it is okay for him to hit us when we do something that they do not want us to do.

Physical abuse per se, and especially of a population that in many ways does not have a voice, is unjustifiable, unreasonable, and unethical.

Q I have a nephew who is nine years old and he has autism. It is said that it is because of vaccination that children have autism. My nephew doesn't talk and we are all very worried for him.

I have another question. Do these children live for a normal life time or do they die soon? Please tell me this because it is a very important question for me.

A Thank you very much for your email. First, I think it is wonderful that you are involved in your nephew's life and can provide support to his parents. As you have no doubt seen, there can be many challenges along with the many rewards of having a child with some type of special need.

You mention the issue of vaccinations. You are correct that there was a period when the scientific community was uncertain about the relationship between receiving vaccinations and having autism. There are still some people who believe in this connection. However, due to the lack of valid scientific research supporting this, it is increasingly viewed as an incorrect attribution for the cause. Current studies have in fact disproven this theory. As you know, there are literally millions of children who receive vaccinations and do not have autism, and many many children with autism who in fact never were vaccinated. I hope this information will help your nephew's parents understand that autism is not something they have caused through any of their actions.

You asked also an important question about life-span. There is no reason to believe your nephew would have a shortened life-span due to his autism. I'm sure this may cause some anxiety if you are uncertain about who will care for him after people of your generation have passed on. This is of course a concern shared by parents the world over. At AFA, we try to help parents focus on teaching skills and communication abilities to the maximum degree possible to foster independence. As society changes, there may be more facilities that develop to help with this process, and your nephew is still young. Some families are working with one another to develop these locally, as well. And there are laws (such as the National Trust Act) that can help in this regard.
If your nephew is not already receiving services, perhaps we can recommend something in the area where he lives.

Q My younger brother has autism. He is 11 years old. He really dazzles us by his intelligence and captivating command over computer programs. He loves music and learns to play piano under guidance of a pianist we have hired. We have admitted him in a mainstream school, so that he learns to sit in school and study there with other students as he rarely shows tendency to play with the children in our colony. He sometimes plays with us and most of his leisure time is spent on playing computer games etc. When my mother teaches him at home, he works well, but he is not as good when he is at school. At school, he shouts loudly and doesn't obey the teacher (she knows about his autism). He often spends his time wandering in the school garden. If he is asked to do his classwork by being spoken to in a harsh tone (that becomes necessary), he does the work where he has to write in his notebook and doesn't pay attention to what the teacher asks him to do. After he completes his classwork, he moves out of the room and starts roaming about. If the teacher tries to catch him, he escapes her hold and does what he has in his mind. He attends the assembly (conducted before the classes begin) peacefully and enjoys when the children sing the anthem together. We are concerned about his attitude at school.

A Thank you for your mail and sharing some of your queries with us. It is wonderful to know that your brother is so skilled on the computer and is doing well in his piano lessons and other lessons at home.

As you are aware, autism is a disorder in which the child attains milestones in a somewhat irregular fashion as compared to children who do not have autism. The areas that are most affected are the ability to communicate, connect with other people, and play. These areas are often late to develop, but more importantly, they develop in unusual ways. They can have can have difficulties both, in understanding communication as well as in expressing themselves. They may often do things which appear socially naive or unusual. This is because having autism means that they do not have the social understanding that the non-autistic person is seen to be born with. We who are non-autistic, learn social rules instinctively: asking the class teacher for help; knowing when and how to speak to a stranger; following through when the class teacher gives a general instruction to the whole class; making friends with the student on the next bench; knowing when to speak and when to give the other a turn. People with autism may have to be taught these in a systematic manner; they often have to learn such social rules cognitively. They may also be disturbed by certain sounds, or be distracted by everyday lights, textures or smells, or have other sensory issues. As I mentioned earlier, play, too may be difficult for our children, as you say is in the case of your brother, because it does require the understanding of social rules. Interacting with family members may just be easier for him because of the familiarity that he has with you and your understanding of him and his needs.

A lot of children with autism may find it much easier to learn during individual work sessions than in a group situation. This is because learning in a group involves dealing with multiple perspectives, as in having to juggle quite a few things at the same time like listening to the teacher; attending to their books/ blackboard/writing down lessons; being in close proximity with other students; waiting; looking at something and listening to instructions at the same time, amongst a few; and our children may have difficulty in all or some of these areas, specially when they have to be attended to all at the same time.

So you see, given the nature of these difficulties, despite being cognitively able, our children may find it difficult to cope in a mainstream school environment which is not structured to the needs of students with autism.

It is possible that your brother is finding it difficult to sit in a designated place for extended periods, or may have some sensory difficulties. It could be a sound or a light or maybe the chair that he sits on that is bothering him. At home, when he is working with your mother, it is possible that his work area is relatively distraction free and his ability to pay attention and stay focused is easier. It may be possible that he is finding it difficult to understand exactly what is expected from him and is thereby finding it difficult to follow his teacher's instructions. Further if his teacher is giving a general instruction, for example 'Everyone, please stand up for prayer time', your brother may not understand that the 'everyone' includes him too. However, when she raises her voice, she may be using his name or maybe through repeated instances he has learnt that it is when his teacher raises her voice that he is supposed to comply with her instructions. As I mentioned earlier, attending to multiple perspectives may be difficult for our children, so when your brother is writing in his book, he may find it difficult to concentrate on the instruction that his teacher is giving him. He may not know exactly what he is expected to do once he's finished with his work and thereby wanders off when his work is done. We need to remember that both waiting and making transitions between activities are often difficult for people with autism. It may also be possible that his peers tease him and he may not be able to tell anyone of what is happening but is getting anxious about the same.

You would appreciate that the above are just some examples. Since we are not aware of the exact circumstances it would be hard for us to understand exactly what your brother is finding difficult in school and we may not be able to give you precise strategies to deal with the same. However, here are some general strategies that may be implemented in his school that may make things easier for your brother:

1. When giving instructions to the entire class, the teacher could use his name as an add-on once in a while, eg, "Every one, X (your brother's name), please take out your math book."
2. Have your brother sit in a place where there are fewer distractions, eg, maybe the first row
3. Provide him with a visual schedule which will help him understand what activity follows another, what is expected of him when he finishes his work and thereby give him predictability in his school day. His class probably will have the week's lesson timetable. Your brother could have the current day's timetable out on his table.
4. You have mentioned that he likes music. If the school permits, maybe giving him a walkman or an ipod to listen to once he's finished his work may help him to wait for the next activity.
5. Interspersing his daily routine with activities of his interest like using the computer. Since your brother is good with computers, would it be possible for him to do some of his lessons on the computer? This would both help motivate him and thus encourage his learning.
6. You could request his teacher to speak to him in a clear, precise, direct manner, giving him the time and opportunity to process what she has said.
7. Providing him with additional visual cues which help him to understand other people's behaviors, understand what is expected from him and thereby manage his own behaviors.
8. The teacher and you may want to discuss your brother's autism with his peers so that they can understand him better and may even want to help him. It is important to remember to be positive when you do this, to mention his strengths along with his difficulties, because your perception and explanation of your brother's autism will reflect on his peers' understanding of and future interactions with your brother.

Painting Techniques by Rutsuko Aizawa of Japan

P Sri Sudha

Recently, I attended an international workshop in Visakhapatnam conducted by Rutsuko Aizawa from Japan. During the session an interesting technique of painting was taught which may be suitable for children with autism.

Tools

- Crayons, Paints, and Water Colours
- Charts or Drawing Sheets
- Soothing music

A group of 12 people (The group is subdivided into three sub-groups and each sub-group comprises of three children and one teacher or a parent)

Step 1

Switch on the music and instruct the group to hold hands with the person next to them. The group then moves around like a train singing a song like 'ring around the roses'. This continues for at least five minutes.

Step 2

Instruct the groups of one adult and three children to sit on the floor. A drawing sheet is given to each participant who writes his/her name or makes some mark to identify their respective drawing sheet.

Step 3

Instruct group members to paint or draw something on their respective sheets for about one minute. After a minute, the drawing sheets are passed to the next person in a clockwise direction. Each participant continues painting/ drawing for one minute. After this, the drawing sheets are once again passed to the next person in a clock wise direction and the painting activity continues for a span of one minute. This continues till the original sheets are back with the respective participant. Finally, the participant is given three more minutes to complete the drawing on that sheet.

Conclusion

This kind of activity may benefit children with autism by improving the following:

- Sharing skills
- Social skills
- Painting skills
- Co-ordination skills
- Time management
- Fine motor skills.

The children were motivated with the help of music as well as encouragement from the adult in their group. At the same time these paintings were not just their own isolated work, but a collective team effort.

Mrs P Sri Sudha is the mother of a nine year old with autism. Contact: srisudha.k@rediffmail.com

Upcoming Workshops at a Glance

Further details available on ***www.autism-india.org*** *shortly*

Amongst the workshops to be held at AFA, is a 2-day workshop on: **'Inclusion in the Mainstream Classroom' on 5 and 6 August 2010**. Children with autism and other social-communication disorders often face difficulties in coping with the demands of the mainstream classroom, in spite of supportive teachers and intellectual and cognitive capability. The workshop will train mainstream teachers, special needs teachers, OTs, SLPs, vocational trainers, psychologists and anyone involved in helping individuals with autism receive an education in mainstream classrooms.

Workshops are illustrated with practical examples based on AFA's hands-on experience and exposure to children with Autism and Asperger Syndrome of varying ages and across the spectrum.

We also have the much awaited 4-day series of workshops for professionals on **'Understanding & Teaching Children with Autism Spectrum Disorders' from 27-30 September 2010.**

This will be followed by a 3-day workshop for parents **Knowing & Teaching my Child with Autism from 19-21 November 2010**. The workshop will build on an understanding of the child with ASD and work through teaching communication, play, social, daily living skills, and behaviour modification.

(RNI No. DELBIL/ 2006/ 23172)

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To continue to receive 'Autism Network' please complete the application below, cut or photocopy, and return it to us as soon as possible.

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Parents: *Associate Member* – Annual: Rs 150/- *Full Member* – Annual: Rs 500/- *Life Member*: Rs 5000/-
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Associate Members receive copies of Autism Network and information on all upcoming events and activities. Full Members, Life Members, Overseas Members and Institutional Members are in addition, entitled to concessionary rates for AFA events and workshops.

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Phone ____________ Email ____________

I am a: (tick all that apply)

☐ Parent ☐ Relative ____________

☐ Professional ____________

☐ Other ____________

If you are a parent of a person with autism, please answer:

Child's name ____________ Sex ____________

Date of birth ____________

Diagnosis (if known) ____________

- I wish to become a member of AFA and enclose:

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